

A Service User's Perspective – Further Reflections

Hilary Pegg

In my report in Newsletter No. 11 (March 2003) describing how it felt as a service user with spirit type experiences and unresponsive psychiatrists, I thanked Dr. Powell and Dr. Sanderson for their help in changing my perspective from a very negative view of what happened. What I was most grateful for was that someone had listened, exactly as Dr Powell had suggested mental health practitioners should do using 'spiritual skills'. I went ahead and followed up some leads Dr. Powell had given me, read 'Taken Seriously', the Somerset Spirituality project, and contacted Jill Sanderson from Ely about Odyssey Groups (Newsletter No. 8). I am shortly to do one of her facilitator courses and am planning to run a group in my hometown. I am also volunteering for the chaplaincy and spiritual care services in our local psychiatric hospital.

But I was still concerned. In 'Mental Health and Spirituality' (Newsletter No.10 Dec 1992), Dr Powell had described mental suffering as 'an experience of pain when it seems to be without meaning or purpose'. My residual pain was that I couldn't fit all that had happened to me in a meaningful framework. Dr. Sanderson had said that my first experience had many features of spirit attachment. I am quite convinced by the work he is doing and have even joined the Spirit Release Foundation, but my second experience I felt did not have those features. I wrote to him again and not hearing from him assumed that I was making excessive demands on his time. However, after a time, I got a reply and the effect of that letter has inspired me to write this second article. I would like to describe how it feels to have a flash of meaning!

What I had experienced in my psychosis partly appeared in my last article. It involved voices and moving of my limbs, talking to God and being in a euphoric state with a sense that everything in the world was ordered especially for me - perhaps what would be described in the literature as a 'grandiose delusion'. But Dr. Sanderson did not use those words. He said, 'How the condition is caused is unclear. Neither neurochemical nor spiritual approaches get anywhere near explaining these extraordinary states'. He then quoted from a French 19th century poet, De Nerval. I recognised immediately the parallels between my experience and his. Finally Dr. Sanderson surprised me by saying that what I had written was a closely observed and beautifully written account and he wanted to read it out, anonymously, on a course he was doing, as an example of psychotic thinking. Amazed, I dug out what I had written and read it with new eyes. There was nothing, I felt, about the writing. What stuck out on my re-reading it was that what I had been describing was a beautiful experience in itself.

It was as if a penny had dropped about one of the many meanings of the word spirituality. Our current biomedical way of looking at things misses out the beauty, the wonder and, to use Dr Sanderson's words, the 'profoundly mysterious' nature of psychotic states. I am reminded of a song from 'The Mikado'.

There is beauty in the bellow of the blast
There is grandeur in the rousing of the waves
There is elegant outpouring when the lion is a roaring
Or the Tiger is a lashing of his tail

Being in a psychotic state is probably mad, probably ill, and no doubt undesirable for the people witnessing it, but it leaves a profound impression on the one experiencing it. At least, it has in my case (although I should add that I cannot speak for anyone else because psychotic experiences, I thought, are not supposed to be talked about and I had not till now been offered a forum in which to discuss them). Dr. Sanderson hadn't given me an actual answer - he had admitted it was a mystery - but he had given me a peg to hang the experience on by the quote from someone else who had had a comparable experience. In the same way, people at a voice-hearing group I went on felt better through meeting others who had the same problem. Isn't part of the meaning of 'meaning' that it is that which we can share? It seems to be the lack of common ground on which to base our beliefs in a 'higher power' that has caused us to use the all embracing word 'spirituality' for what we believe in, knowing that it finally gives us something in common.

Being affirmed in this way has led me to think about what would be helpful to me and others like me. Yes, we would like to be listened to, but I think it could help to work in a group talking about our experiences, acknowledging and even celebrating the mystery of it, and reading accounts of other experiencers. I have been on two courses about working with psychosis but neither suggested this. They were both concerned with getting away from the experiences. The best group I have been on was the hearing voices group in which we looked face on at the experience of voices, even though for the other people on the course they had been distressing. For some people talking about them gave them control over them.

I would also like to see a change in the tone of literature for patients about manic episodes. The Expert Consensus Treatment Guidelines for Bipolar Disorder: Guide for Patients and Families was the leaflet I had read which had so shocked me when the psychiatrist had thrust it into my hand. It says: 'In very severe cases, there may be psychotic symptoms such as hallucinations (hearing or seeing things that aren't there) or delusions (firmly believing things that aren't true)'. As a summary of my experience, this is almost offensive. It doesn't say, for example, 'some people may experience a profound sense of meaning, spiritual in its quality' or 'there is much in mental illness remains a mystery'. It talks about 'having an inflated feeling of power, greatness or importance'. This is a very disparaging way of describing what De Nerval described in these terms: 'I seemed to myself a hero living under the very eyes of the gods'. A move has been made to change the term Manic Depression to Bipolar Affective Disorder and there is no reason why descriptive terms could not be changed to have user-centred language or actual quotes from service users. In the user's experience I'm sure hallucinations are not 'not there' and delusions are not 'not true'. In my psychotic states I have experienced meaning to such a high degree that I would say it was a spiritual experience. After the experience I was left to wonder alone what had happened, with nothing but a diagnostic label round my neck.

There may be reasons why such an approach is not possible. Being too 'user-friendly' might affect the professional distance required by the practitioner. It certainly does not sound very expert to say in public that the reductionist perspective may not be the only explanation or that mental health is a mystery. Yet there are moves afoot in the National Health Service to call us users with a very different kind of knowledge 'experts by experience'. We are being asked to go on clinical governance committees to talk about the quality of services and get involved in training staff. I for one have been helped by psychiatrists in your group who take the wider picture, admit that we live in a mysterious universe and are prepared to use poetry and not biomedical language to express mental states. I may be unusual in wanting my experiences acknowledged, but I suspect I am not. I am on an Internet forum called

'psychosisspirituality' on which people discuss the more esoteric side of psychosis. I wrote there about my experience and received a reply from a member to the effect that defining us can make us feel small or large. Being told three times I had manic depression in a ward round of ten people made me feel small, reduced by reductionism. Having my experience valued and used can make me feel large.

In the early days, which I believe is common for people coming down from manic states, I tried to get my experiences back. I have lain sleepless at night using the call signs the spirits gave me in case they might return. I have been sorely tempted to stop the medication to get back to that ecstatic state. But I know my husband does not want to see me 'mad' again and with the mania I know there is the possibility of the depression. I don't do that now. What is helping me to put the experiences in context is this: not necessarily knowing what caused them, I can live with the word mystery, but knowing I am not alone, I can continue to communicate with people who share an interest in what Dr Powell has called 'the further reaches of consciousness'.

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